

## Nemours Children's Hospital

# 2016 Community Health Needs Assessment Implementation

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Nemours Children's Health System is dedicated to one promise: To treat each child as if they were our own, doing everything within our power to help each child grow up healthy and reach their full potential. As one of the nation's largest pediatric health systems, we integrate innovative patient care, research, education,

#### Nemours in Florida

Nemours Children's Hospital is home to experienced teams and world-class experts accustomed to working together to care for kids, newborns to age 18. The Emergency Department (ED) at Nemours Children's Hospital is equipped to handle all kinds of pediatric emergencies. Unlike a general emergency room, our Emergency Department is dedicated exclusively to the care of children from newborns to age 18. Nemours is home to many specialized pediatric programs, some of which offer care never before available in their respective regions. When a specialist is necessary, our pediatricians have immediate access to renowned experts in more than 30 pediatric specialties including:

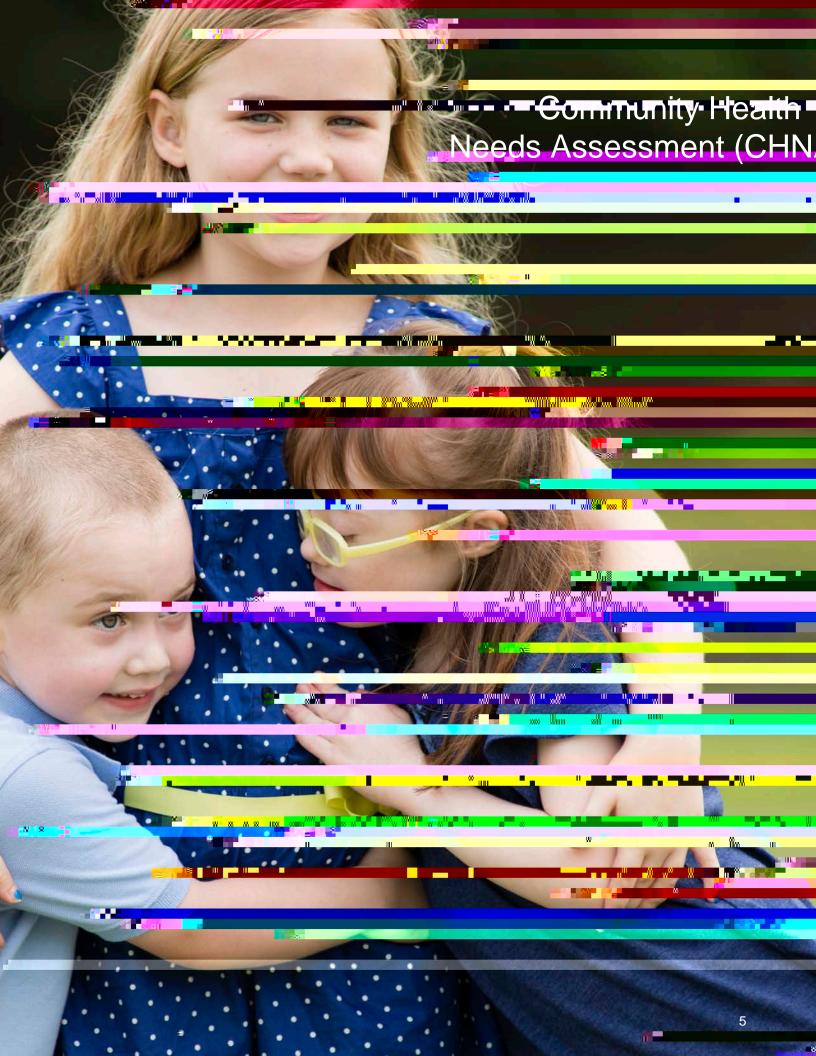
Nemo Ca diac Cen e in Florida opened in 2016, expanding our existing expert cardiology services to include integrated care for kids with all types of heart disease.

Nemours pedia ic in e en ional adiologi are at the forefront of imaging and image-guided therapies, offering innovative ways to diagnose and treat conditions in a minimally invasive way. Of the 100 fellowship-trained pediatric interventional radiologists in the United States, Nemours employs three in Central Florida.

Our ne om c la p og am offers the area's only Muscular Dystrophy Association-approved clinic, and Nemours Children's Hospital is one of only four locations in the world conducting the rst targeted drug trial for spinal muscular atrophy.

Nemo o hopedic peciali develop treatments to help children with bone, muscle and joint conditions become more independent.

Our Va c la Anomalie P og am



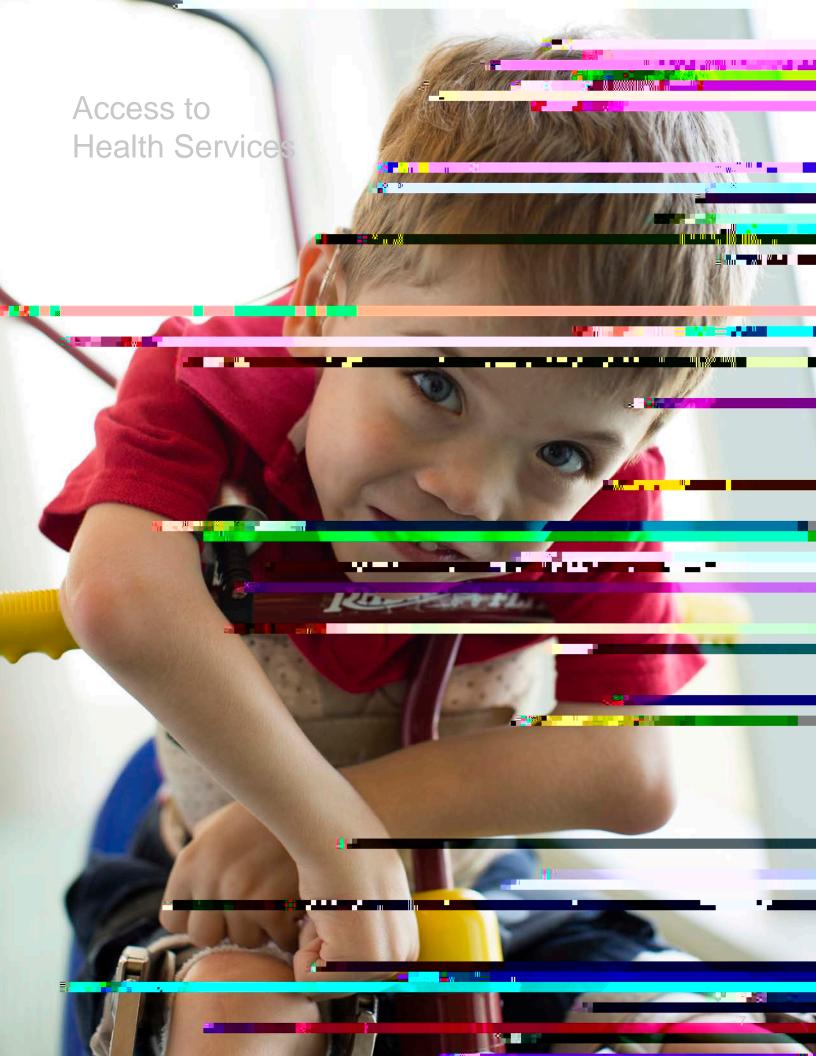
During 2016, Nemours embarked on a journey to identify the child and adolescent health needs of the communities near Nemours Children's Hospital (NCH) in Central Florida. Nemours engaged Professional Research Consultants, Inc. to assist in determining the health status, behaviors and needs of children and adolescents in our immediate service area which has been de ned as households with children in Brevard, Orange, Osceola and Seminole counties in Florida.

The assessment was comprised of both qualitative and quantitative data including a customized child and adolescent health survey, focus groups, public health data, vital statistical data and other benchmark data on the health of children in Central Florida. To ensure the ever-changing needs of the community are continuously captured, the CHNA is conducted every three years using the same methodology. The 2016 administration of the CHNA resulted in the following areas of opportunity representing the signicant health needs of children and adolescents in the community.

## **Areas of Opportunity**

- § Access to Health Services
- § Prenatal, Infant & Child Health
- § Injury & Safety
- § Nutrition, Physical Activity & Weight

After reviewing this Community Health Needs Assessment report, Nemours' Central Florida leadership team met to evaluate and prioritize the top health needs for children in the community. Data for the community were examined, and attendees .2() ldren in the community. Data f7ep/S Data fessn f7ep/S Da



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#### **Nemours CareConnect**

Nemours launched CareConnect (Nemours' direct-to-consumer telemedicine program) in November 2015, which allows families to hold a video visit with a Nemours pediatrician through a smart phone, tablet or home computer. The service is available 24/7, anywhere in Florida. Nemours is available when families need answers. Whether it's the middle of the night or during regular of ce hours, Nemours board-certi ed specialists are available at the push of a button.

Nemours also uses CareConnect in collaboration with 31 provider organizations including six hospital af liates in Florida. When working with a partner hospital, Nemours pediatric subspecialists are able to remotely access a patient's medical record and directly consult with their provider to determine the safest, most appropriate care. Using this model, Nemours pediatric experts are able to in uence delivery of children's health care outside of our system, ensuring that all children have access to the best pediatric expertise, and allowing families to remain in their



## Improving Outcomes & Safety for Mothers & Infants

#### **Nemours Fetal Care Center**

Nemours is dedicated to serving children and their families at every stage of life. The Fetal Care Center at NCH provides expert maternal-fetal and perinatal care to Central Florida mothers-to-be facing high-risk pregnancies or problems with their unborn child. Although Nemours doesn't deliver babies, we co-manage care with mom's doctors and coordinate services focused on baby's health before, during and after birth. The Fetal Care Center is designed with pregnant patients' health in mind and provides a dedicated clinic space, prompt scheduling, and referrals to pediatric specialists that are arranged and tracked by the Fetal Care Center.

#### Milk Bank of Florida

Breast milk is the preferred feeding for all infants and offers bene ts not found in any substitute. It provides "passive immunity" for the baby, protecting the baby from a wide variety of bacterial and viral illnesses. Breastfeeding also can lead to better cognitive development, as well as physical and emotional bene ts due to skin-to-skin contact. Because early nutrition is a signi cant contributor to healthy child development, NCH provides a storage location to support milk banks as well as a neonatal practitioner and international board-certi ed lactation consultant. To support breastfeeding and infant health, Nemours hosts a weeklong certi ed lactation counselor training course once a year, providing education, certi cation and resources to providers and breastfeeding advocates.

#### **Neonatal Resuscitation Program**

NCH provides classroom instruction in the Neonatal Resuscitation Program (NRP)<sup>TM</sup>. NRP is an educational program based on the American Academy of Pediatrics and the American Heart Association guidelines for cardiopulmonary resuscitation and emergency cardiovascular care for newborns at time of delivery. NRP introduces concepts and basic skills of neonatal resuscitation. Successful completion of the online written course is required before participants attend the classroom portion of the NRP course. The course is open to all health care providers in the Central Florida community for a nominal fee.

## S.T.A.B.L.E. (Sugar, Temperature, Airway, Blood pressure, Lab work, and Emotional support)

NCH offers classroom instruction for the modular instructional program known as S.T.A.B.L.E. S.T.A.B.L.E is a neonatal education program for health care providers focusing on the post-resuscitation and pre-transport stabilization care of sick infants. The course is available to all health care providers and ancillary personnel for a nominal fee.

#### March of Dimes of Central Florida

The March of Dimes in Central Florida is a long-time partner of Nemours, supporting the hospital through generous donations and support. Throughout the years, Nemours Associates have become heavily involved in March of Dimes' events and fundraisers with collaborative efforts resulting in signicant dollars raised to support research, educational opportunities and support services for parents, caregivers and families. Donations from the March of Dimes also supports the education of medical and nursing staff in the latest developments and indings regarding neonatal and perinatal diagnosis, treatment and plans of care for high-risk newborns.

While the majority of children in the TSA were not seriously injured in the last year, 13.3 percent sustained injuries serious enough to require medical treatment. Of these respondents, more than two-thirds (67.3 percent) reported that their child was seriously injured once in the past year, 22.9 percent of respondents reported two incidents and 9.8 percent said their child needed medical treatment for an injury three or more times in the past 12 months. When asked what the child was doing when the injury occurred, parents mentioned activities such as organized sports, playing, and falling or tripping. The prevalence of serious injury among children in the TSA is highest among boys, teens, and White and Hispanic children.

The number one leading cause of death among children ages one to 19 years is accidents, primarily drowning in children ages one to four and motor vehicle accidents in children age 15 to 19. Approximately 91.8 percent of respondents reported that their child "always" wears a seatbelt (or appropriate car seat for younger children), a signi cant decrease in seatbelt usage from 2013. The lowest usage was reported among children under four years of age at just 84.4 percent.

#### Initiative

Increase awareness of and participation in community safety and injury initiatives and programs.

#### Goals

- A. Provide Safety/Injury Education to patients and families.
- B. Create targeted Safety/Injury Initiatives to serve the needs of the community.

#### Metrics

- 1. # of attendees at our School Health Conference
- 2. # of players served through USTA Player Development Program

## **Education and Training Initiatives**

### Car Seat Safety Program

In addition to Nemours' NICU discharge education program, NCH provides car seat safety resources for all children leaving the hospital. If a family does not have an appropriate car seat to safely transport the patient, NCH will provide one at the time of discharge. In addition, Nemours Certi ed Car Seat Installation Technicians review best practices for car seat safety and provide detailed instruction on how to install a car seat into the family's vehicle.

## Hands-OnlyCPR Training Initiative & World Heart Day

Hands-Only<sup>TM</sup> CPR is cardiopulmonary resuscitation without mouth-to-mouth breaths. It is recommended for use by people who see a teen or adult suddenly collapse in an out-of-hospital setting, such as at home, at work or in a park. In the event of a cardiac emergency, people are more likely to perform Hands-Only<sup>TM</sup> CPR and ultimately save a life. The Nemours Cardiac Center is working together with the American Heart Association, Central Florida school districts, re departments and other community organizations to promote and conduct Hands-Only<sup>TM</sup> CPR Training throughout Central Florida.

On World Heart Day, September 29, 2016, people across Orange County took advantage of free, Hands-Only™ CPR training. World Heart Day was founded in 2000 to inform people around the globe that heart disease and stroke are the world's leading causes of death, claiming 17.3 million lives each year. More than 28,000 people participated in the CPR training sessions, including 200 participants who trained at NCH.

Along with Nemours Children's Hospital, the following organizations offered the training sessions:

- **§** Orange County High Schools
- § Orlando International Airport
- § University of Central Florida
- **§** DoubleTree Suites by Hilton
- **§** Catalyst Community Church
- **\$** Children's Safety Village
- **§** Lake Whippoorwill KOA
- § SeaWorld
- S Ocoee Fire Station #25

#### Nemours' School Nurse Health Conference

In August, Nemours hosts an Annual School Nurse Health Conference dedicated to school nurses and other school health professionals from across Central Florida. The program includes training for typical pediatric care in a school setting such as management of injuries, allergies, asthma, diabetes, substance abuse, mental health and response to medical emergencies. The conference will include hands-on training through the Nemours Children's Hospital simulation lab and small group discussions on topics relevant to school health.

#### YMCA Safety Around Water Program

NCH supports the YMCA's Annual *Safety Around Water* event, a four-day introductory swim program for youth ages four to 12 years. During the event, nearly 5,000 children receive water safety education and character development lessons in a safe, structured environment. YMCA Swim Academy instructors instill a love of the water while helping kids and parents build safety skills and knowledge. The program is free, open to the public and is offered at 20 YMCA locations across Central Florida. Nemours is also collaborating with the YMCA for Florida's Healthy Kids Day on Saturday, April 29.

## Sports Medicine – Prevention and Treatment

## United States Tennis Association (USTA) Collaboration for Sports & Injury

Some of the nation's top youth tennis players optimize their performance through sports medicine programs designed by the Andrews Institute for Orthopaedics & Sports Medicine and Nemours Children's Health System. The two organizations have come together to serve as the Of cial Medical Services Providers for the USTA National Campus, the Home of American Tennis.

Nemours and Andrews Institute provide a team physician, program director, sports nutritionist and athletic trainers for the USTA National Campus in Orlando's Lake Nona Medical City. These specialists offer pediatric-focused injury prevention, rehabilitation and therapy along with athletic performance programs focused on optimizing a young athlete's performance.

# Nutrition, Physical Activity & Weight

Obesity and Nutrition was identied by families in the TSA as the number one perceived health issue for children and teens. The prevalence of overweight and obese children in the total TSA is more than the national average, a signicant increase from 14.4 percent in 2013 to 19.3 percent in 2016. Obesity was reported highest among boys, children between the ages of ve and 12, children in low income households and Hispanic and white children.

## **Programs and Education**

#### **Healthy Choices Clinic**

The Nemours Healthy Choice Clinic, an outpatient pediatric weight management program, provides multidisciplinary care to over 300 children in the Central Florida community who are clinically obese, or overweight with related risk factors. The multidisciplinary team, including physicians, nurses, health coach, registered dietitians, exercise specialists and mental health counselors, works with patients and families to adopt long-term, sustainable lifestyle changes that can lead to signicant improvements in children's health and well-being. To increase access to the Healthy Choices Clinic, Nemours now offers this service at satellite clinics in Downtown Orlando and Brevard County.

In order to further extend our clinical expertise and provide convenient access to obesity and nutrition counseling, our researchers have developed a pilot program using telehealth technology. Nemours Health Coaches connect with families through the Nemours CareConnect application to provide goal setting and behavioral counseling to patients in the comfort of their own home. Nemours supports the patient-centered medical home model by providing the patient's primary care physicians with clinical decision support tools and access to the patient's encounter with the health coach.

## KidsHealth.org: Health Education for Patients and Families

Nemours Children's Health Media/KidsHealth maintains a website with more than 10,000 articles, animations, movies, fact sheets, recipes and more, in English and Spanish, around a wide range of medical, emotional, behavioral, safety and developmental topics. The site has dedicated areas with age-appropriate content created speci-cally for parents, kids and teens. All content is reviewed and systematically updated for accuracy and balance by Nemours pediatricians and experts in the subject matter. The site is free to use, requires no registration and is free of advertising.

## Florida Prevention Initiative (FPI)

## Wide Dissemination and Targeted Saturation of Community Prevention Programs

Nemours Children's Health System has a tradition of working beyond the walls of our facilities and in the community where families live, work and play. We provide a continuum of care from outpatient and inpatient services, to community outreach and child health advocacy. The Nemours Florida Prevention Initiative (FPI) lls a strategic role in our integrated health system through health promotion and disease prevention activities, reaching not just the children who use our medical services, but also those who are part of our community, currently focusing on obesity prevention in early childhood.

FPI's current focus on birth to ve years is based on the recognition that habits are readily malleable in the early years. Early learning confers value on acquired skills, and early prevention beats the cost of later remediation. With almost 16,000 young children in Central Florida impacted by FPI training for child care providers and through focused initiatives to saturate targeted communities, the program is moving towards a tipping point in which Nemours' healthy eating and physical activity messaging is widely recognized, adopted and sustained.

#### Wellness Policies in Early Care and Education (ECE)

Nemours FPI aims to improve environments, policies and practices to support healthy behaviors in early childhood education (child care) settings through the development of customized wellness policies. Our approach includes working with ECE professionals through technical support to increase their knowledge of nutrition, physical activity, recommendations for regulating screen time and best practices to help create healthier environments that support children's development of positive associations with healthy eating and activity. Nemours aims to increase access to active play, healthy food and healthy beverages, as well as support breastfeeding and staff wellness.

#### Leveraging Community Partnerships to Disseminate Messaging

Nemours FPI is a key partner in Central Florida's ECE arena, serving on various boards, committees and task forces with the shared goal of children's health. With feedback from community partners, ECE programs and families, we have developed science-based, educational materials around healthy living to share in the community and in our clinical practices. Nemours works with community partners to spread consistent health messaging across the TSA and empower children and families to practice healthy behaviors where they live, learn and play. Developing a united effort and co-branding our community resources with local school districts and county health departments has been of great bene t to the Central Florida community.

Nemours' Community Resources include:

§ 5-2-1-Almost None – broC support to increase their knowledge of nutriti5t 10 0dy.8 0 Td (5-2-1-Almost None – bdCrease

## Other Community Initiatives

## Development of Culinary Medicine Elective at UCF College of Medicine

The University of Central Florida College of Medicine, in collaboration with Nemours, has developed a Culinary Medicine elective that will combine medical nutrition, dietetic and culinary concepts that students will use to more effectively counsel patients on lifestyle skills. The elective will allow for hands-on experiences in professional kitchens, under the supervision of professional chefs and registered dietitians to improve medical students' knowledge and skills in counseling patients about healthy lifestyles, nutrition and cooking. Effective counseling will help patients achieve and maintain optimum health. The Culinary Medicine elective seeks to demonstrate the powerful triad of physician, dietitian and chef in health promotion and disease prevention. Nemours physician, Rob Karch, MD, was instrumental in developing this elective's curriculum and hosts hands-on experiences at the NCH Teaching Kitchen.



# Asthma & Other Respiratory Conditions

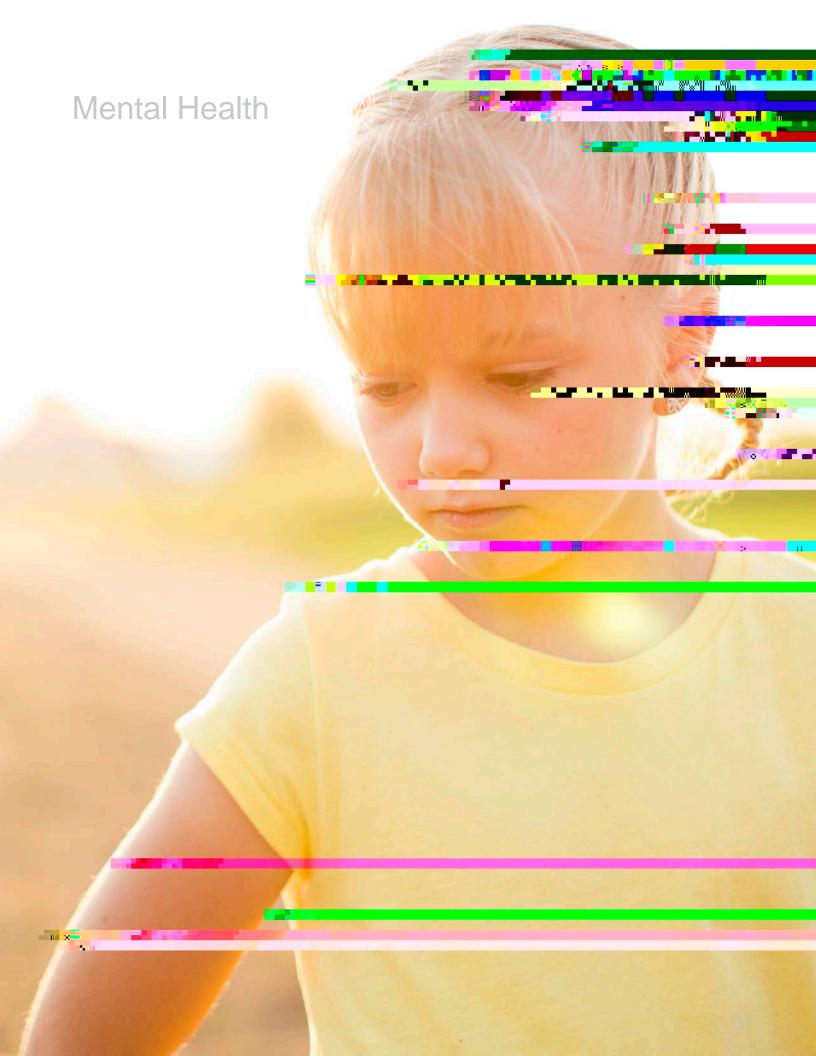
## **Programs and Initiatives**

#### Cystic Fibrosis Clinic

One of the top concerns reported by our needs assessment was the correlation of mental health with physical health. One example of how Nemours focuses on the whole health of children is in our cystic brosis clinic. The gastroenterology, endocrinology, otolaryngology, nutrition and psychology departments at Nemours work together to provide patients and patient families with the education and resources they need for dealing with cystic brosis on a day-to-day basis. Due to the mental and emotional effect that health conditions have on children, we make behavioral health counselors and social workers available to patients and families receiving inpatient treatment and outpatient care in our clinics.

#### Collaboration With Nemours Primary Care Providers

The Nemours Pediatric Pulmonary Division collaborates with Nemours Children's Primary Care to provide continuous education on the use of of ce spirometry, asthma education modules and asthma action plans. In keeping with the patient-centered medical home approach, Nemours understands the critical role that our primary care providers play in the day-to-day management of asthma. Our providers work with families to develop asthma action plans to help avoid asthma triggers, prevent—are-ups and keep children out of the emergency room.



## Mental Health

The majority of TSA respondents with children ages—ve to 17 years rate their child's emotional or mental health — which includes stress, depression and problems with emotions — as "excellent" (39.8 percent) or "very good" (30.2 percent). However, 11.3 percent of parents in the TSA reported that their school-age child's emotional or mental health is "fair" or "poor," which is double the national average (5.5 percent). This trend has increased signicantly over the last three years. Very low-income families reported the highest level of "fair" or "poor" mental health at 20.2 percent.

Among Orange County high school students, 9.1 percent report attempting suicide in the past year, this rate is signicantly higher in high school girls than boys.

Among TSA parents of children age 5-17, 5.1 percent indicate that their child has been diagnosed with autism, which is higher than the national benchmark of 1.4 percent. Of the children reported with autism, 11.5 percent of parents characterize their child's autism as "severe."

A total of 13 percent of children in the TSA are reported to have ever suffered from or been diagnosed with ADHD, which is higher than the national average of 8.7 percent. Of the children reported with ADHD, 9.7 percent of parents characterize their child's ADD/ADHD as "severe."

#### Early Autism Screening, Treatment, & Training Program

NCH is proud to offer the region's most comprehensive program for children diagnosed with autism spectrum disorder. Through early screening and educational training, the autism specialists at Nemours are actively involved in identifying autism spectrum disorders at an early age, while teaching parents and care providers how best to help children thrive. We also help advocate for children to receive available services in the community and in school.

Diagnosing children with an autism spectrum disorder is complex and requires comprehensive evaluation by experienced pediatric specialists in different medical disciplines. Early intervention is proven to signicantly improve symptoms and offer children the best chance to adapt, grow and thrive into adulthood. As a regional referral destination, we're uniquely experienced to evaluate, diagnose and treat autism spectrum disorders in children, from infants to adolescents. Our autism experts include a team of pediatric neurologists, psychologists, psychiatrists, behavior analysts, therapists (speech and language, physical and occupational) and others who work with you to give your child the best chance for success at home, at school and in the future.

Research shows that early autism screening using a simple parent questionnaire can help identify the signs of autism and other developmental disorders in children as young as 12–18 months. Through an initiative with our pediatric primary care network, our autism specialists provide local pediatricians with the tools to recognize the signs of autism so we can begin treatment as early as possible, for the best results possible.

#### Imbedded Clinicians Within Medical Specialty Clinics

One of the top concerns reported by the TSA is correlation between mental health and physical health. At Nemours, we take a holistic approach to health care and treat every child as if they are our own. The Nemours Cystic Fibrosis Clinic is an example of how we develop multidisciplinary teams to treat the "whole" child.

There is an emotional toll on children living with cystic brosis (CF) and they often have periods where they cannot interact with other children because of the risk of developing infections. Nemours CF experts understand how lonely this can be, so we've developed resources to help children cope with these feelings. Nemours licensed clinical social workers provide comprehensive psychosocial assessments, resource coordination and mental health screenings for patients and families living with CF. The hematology, oncology and psychology departments at Nemours work together to provide patients and patient families with the education and resources they need for dealing with cystic brosis on a day-to-day basis. Due to the recognized mental and emotional effect of health conditions on children, we make behavioral health clinicians available to patients and families receiving inpatient treatment and outpatient care in our clinics. In addition, we offer newsletters and support groups, and often pair children of similar ages so patients can develop friendships among their peers.

#### Pain Management Clinic

The Nemours Pain Management Clinic is staffed by physicians of different specialties and other nonphysician health care providers who specialize in the diagnosis and management of patients with chronic pain. Our facility differs from a multidisciplinary pain center only because it does not include research and teaching activities in its regular programs. A multidisciplinary pain clinic may have diagnostic and treatment facilities which are outpatient, inpatient or both. At NCH, the pediatric pain program consists of a primary physician, who is board-certied in both pediatric anesthesiology and pediatric pain management, a psychologist, a social worker, a nurse/coordinator, and a physical and occupational therapist.

## Community Partnerships & Collaborations

The Nemours Behavioral Health Department is actively working with community partners including the Orange County Mayor's Youth Mental Health Commission to address mental health issues in our Central Florida community.



# Vision, Hearing & Speech

Nemours pediatric ophthalmologists encourage early vision screenings by primary care physicians at newborn visits and at all well-child visits. In fact, the American Academy of Pediatrics (AAP), the American Association for Pediatric Ophthalmology and Strabismus (AAPOS) and the American Academy of Ophthalmology (AAO) all recommend that children's eyes be examined at timely intervals. This is because pediatric eye exams result in early detection and treatment of eye disorders leading to more successful treatment outcomes and protecting a child's vision. Within the TSA, a total of 81.6 percent of parents reported that their child has received an eye exam within the past three years. However, 16.3 percent of parents reported that their child has never received an eye exam.

In addition to vision screening, hearing evaluations should start at birth and continue on a regular basis throughout life. Approximately 11 percent of the TSA indicate that their child has never received a hearing test, which is slightly higher than the national average.

#### **Spot Vision Screenings**

The Nemours Ophthalmology Department and FPI partner together to providing free vision screenings at community events and promote early detection of vision problems. A handheld, portable device allows Nemours to take a Spot™ Vision screener to these events and into preschools in order to reach children who do not have access to routine screenings. This Spot Vision screener reduces the time it takes to determine if a child has a potential vision concern which, if not treated, can result in irreversible vision problems later in life.

### Our Healthy Eyes

Nemours' *Our Healthy Eyes* is a collaborative program developed by Nemours FPI and Nemours BrightStart! in order to reach young children, educate their families about eye and vision health, and identify those who need follow-up care. Nemours provides early child care centers with a lesson plan about eye and vision health. The one-day lesson is followed by a vision screening event where Nemours provides additional resources including a family newsletter and information for follow-up care.

## **Eyeglass Recycling**

In most dresser drawers, one can nd a pair of eyeglasses that are no longer used. That same pair of eyeglasses can change another person's life. That's why the Nemours Florida Prevention Initiative, in partnership with the Lions Club's Recycle for Sight program, collects used eyeglasses. These glasses are delivered to Lions Club recycling centers where they are cleaned, sorted, packaged and distributed to needy children and adults in our community, free of charge.

## **Our Healthy Ears**

Modeled after *Our Healthy Eyes*, Nemours' *Our Healthy Ears* is a collaborative program developed by Nemours Florida Prevention Initiative and Nemours BrightStart! in order to reach young children, educate their families about ear health and hearing, and identify those who need follow-up care. Nemours provides early child care centers with a lesson plan about the ear and hearing. The one-day lesson is followed by a hearing screening event where Nemours provides additional resources including a family newsletter and information for follow-up care.

#### **Newborn Hearing Screening**

Most states have a statute requiring universal newborn hearing screening. Since October 1, 2000, newborn hearing screening has been required, unless the parent objects, for all newborns in Florida. The intent of this statute is to provide a statewide comprehensive and coordinated interdisciplinary program of early hearing impairment screening, identication and follow-up care for newborns. The goal is to screen all newborns for hearing impairment in order to alleviate the adverse effects of hearing loss on speech and language development, academic performance, and cognitive development. In addition to providing newborn screening in our own Neonatal Intensive Care Unit, Nemours audiology provides the service for some of our hospital partners including Osceola Regional Medical Center. From the start of this service in June 2016 through December 2016, Nemours screened 1,251 infants.

#### The Nemours Cochlear Implant Program

Cochlear implants can help many children who are born deaf or who have become deaf to hear conversation and sounds. The Nemours cochlear implant program takes every aspect of a child's auditory (hearing), developmental and social health into account. Our multidisciplinary team of ENT specialists, audiologists, nurses and social workers collaborate to help each child maximize their communication potential. Nemours assists parents to become experts on their child's hearing loss and learn how to be their child's advocate in all settings.

#### Nemours Children's Hospital Audiology Division

NCH's Division of Audiology has the largest group of audiologists in Central Florida and offers comprehensive pediatric audiometric assessment and management, including sedated auditory brainstem response (ABR) testing and a hearing aid dispensary. In addition to newborn hearing testing and the cochlear implant program, Nemours provides other treatment and services including implantable hearing devices, osseointegrated devices (i.e., bone-anchored hearing aids), and treatment for auditory processing disorder and auditory neuropathy spectrum disorder. In order to expand access and convenience, the Division of Audiology offers services at four locations in the Central Florida region.

## Speech Language Pathology Division Highlights

NCH's Division of Speech Language Pathology in the Department of Rehabilitation Services provides specialized therapy for children with communication de cits secondary to hearing loss. In addition to providing auditory verbal therapy as part of the cochlear implant program, the division is involved in several other collaborative endeavors including:

§ diagnostics as part of the autism clinic (multidisciplinary team)



#### SECONDARY HEALTH CONCERN

# Potentially Disabling Conditions

From 2013 to 2016, prevalence of activity limitations in the TSA has increased from 8.8 percent to 10 percent due to conditions such as autism, ADHD/ADD, mental health, joint problems, allergies, asthma, Down syndrome, cardiac care, broken bones and other long-term conditions. Essentially, one in 10 children in the TSA is limited or prevented in some way in their ability to do things most children of the same age can do because of a medical, behavioral or other health condition. For children with activity limitations, the vast majority (90.2 percent) are living with a condition that is expected to last 12 months or more.

Oftentimes, these children need support from multiple pediatric specialists. For this reason, the Nemours Model of Care is based upon a uni-ed physician practice. At Nemours Children's Hospital, a team of physicians and subspecialists are available to serve the unique needs of our patients and families in one place. This provides Nemours with an invaluable resource, the ability to pull together a multispecialty team within minutes to treat even the most complex cases.

## **Programs and Initiatives**

### Medically Complex Coordination Clinic

Care coordination plays an integral role in treatment for children with complex medical conditions. For this reason, Nemours has established a special consultative service, the Nemo Medicall Comple Coo dina ion Clinic, to bring coordination of care to children with special needs. In partnership with our patients' primary care physicians, the coordination clinic helps identify each patient's special connects family members to community resources, nutritional guidance and psychosocial support. The Nemours Medically Complex Coordination Clinic supports patients seen in the following clinics:

- **§** Rheumatology Clinic
- S Cystic Fibrosis Clinic
- § Diabetes Clinic
- § In ammatory Bowel Clinic
- **§** Scoliosis Clinic
- **§** Wound Care Clinic

## Multidisciplinary Muscular Dystrophy Clinic

Nemours Children's Hospital provides a true multidisciplinary approach to muscular dystrophy care. Our team includes experts in orthopedics (bones and joints), pulmonology (lungs), neurology (brain, spine and nerves), genetics (DNA that determines heredity), physical and occupational therapy (improving muscle performance and motor skills), cardiology (heart), nutrition (help for kids with trouble eating), and psychology (behavioral and mental health). The Muscular Dystrophy Clinic at Nemours Children's Hospital is the only program in Central

## Redesigned ER Model Limits Stressors for Children With Autism Spectrum Disorder

Eliminating unnecessary stimulation in the Emergency Department, NCH has developed a new model for providing care to children with autism spectrum disorder, developmental delays and other behavioral conditions. The redesigned care model is specially designed to reduce poor outcomes and negative experiences caused by sensory overstimulation in a typical Emergency Department setting.

NCH's Emergency Department instituted a pilot program based on the limited research available. Named "Respecting Each Awesome Child Here" or REACH, it is one of the street in the country to adapt care to the needs of children within the Emergency Department. The complete care model covers all aspects of a visit:

- **§** A i al: Families are instructed to alert Emergency Department staff if a child has autism spectrum disorder or another behavioral condition. From there, families and children are offered options such as headphones, sensory brushes and other resources to help distract children from overwhelming sights and sounds. Patients are also offered the option to occupy a separate, quiet waiting room or playroom while waiting to be seen.
- **§** In ake and A e men: The health care team on the Emergency Department oor is noti ed of the arrival of REACH families, ensuring the special accommodations are provided. A Child Life specialist is brought in to assess the situation and to make sure that children and parents are comfortable. Frontline staff can decrease stimulation for children by dimming lights, reducing use of unnecessary monitors and limiting the number of caregivers in the room at one time.
- **§** T ea men: Families are consulted on their child's preferences and any adverse reactions to medications or to behavioral triggers, enabling providers to expedite decision-making to comfort the patient. The health care team sets up a REACH order that can be followed to expedite choices regarding consults, medications, tests and environmental adaptations.

Prior to instituting REACH, health care personnel at NCH's Emergency Department underwent education and training to learn new techniques and the capabilities of the tools available. Three research studies are underway to evaluate the pilot program and similar efforts, including assessing how emergency departments across the country

### Camp Boggy Creek

Nemours Children's Health System is a long-time medical partner of Camp Boggy Creek, founded in 1996 by Paul Newman and General H. Norman Schwarzkopf. The camp was created so that every child, no matter their illness, could experience the transformational spirit and friendships that go hand-in-hand with camp. Located just a short drive from Orlando, the 232-acre camp serves children ages seven to 16 who have been diagnosed with chronic or life-threatening conditions. Camp Boggy Creek is able to serve thousands of campers and their families through activity-packed weekly and weekend camp programs. Nemours partners with Camp Boggy Creek as a sponsor for special camp events and supports the medical clinic with physician volunteers.

#### Come Dance With Us

In 2016, NCH, Orlando Health and the Orlando Ballet collaborated on an event titled *Come Dance With Us.* The program offered 10 children with special needs the opportunity to attend the Orlando Ballet for an introductory ballet course and perform an original score from *Beauty and the Beast.* This unique program required a multifaceted team consisting of many volunteers including two Nemours physicians, ve Nemours physical therapists, three Orlando Health physical therapists and four professional dancers from the Orlando Ballet.

## Be The Match - Bone Marrow Registry Drive

For patients diagnosed with leukemia, lymphoma and other life-threatening diseases, a bone marrow or cord blood transplant may be their best or only hope for a cure. Yet 70 percent of patients who need a transplant do not have a fully matched donor in their family. For this reason, NCH partners with Be The Match® to host bone marrow donor drives for Associates and the general public. Over the past 25 years, Be The Match®, operated by the National Marrow Donor Program® (NMDP), has managed the largest and most diverse marrow registry in the world. Every day, they work tirelessly to save lives through transplants. Nemours supports Be The Match® to grow the donor registry, support pediatric patients and advance the science of transplants.

#### SECONDARY HEALTH CONCERN

## **Diabetes**

Every year in the United States, 13,000 children are diagnosed with Type 1 diabetes, and more than one million Americans deal with the disease every day.

Within the TSA, approximately 2.8 percent of children ages 0 to 17 have been diagnosed with diabetes by a doctor or other health care provider, which is considerably higher than the national benchmark (0.7 percent). Since 2013, the prevalence of childhood diabetes in the TSA has grown signicantly from 1.3 percent to 2.8 percent. Those more likely to have been diagnosed with diabetes include children ages 0 to 4, Black and Hispanic children.

## The Nemours Pediatric Diabetes Program

Nemours understands that a diagnosis of diabetes can be very overwhelming for a family. And, although it's a condition that will always be a part of a child's life, early intervention is key to successfully managing the disease. At Nemours, our experienced, board-certi ed pediatric endocrinologists provide the answers and help that families want and need.

Furthermore, many of our investigative researchers are involved in research projects funded by institutions such as the National Institutes of Health, Juvenile Diabetes Research Foundation (JDRF), Patient-Centered Outcomes Research Institute, Genentech Foundation for Endocrine Research and the Abbott Fund, among others. Nemours often offers clinical trials related to diabetes. A clinical trial is a study that evaluates new medicines, new devices, new treatments or new applications for old treatments.

#### **TrialNet**

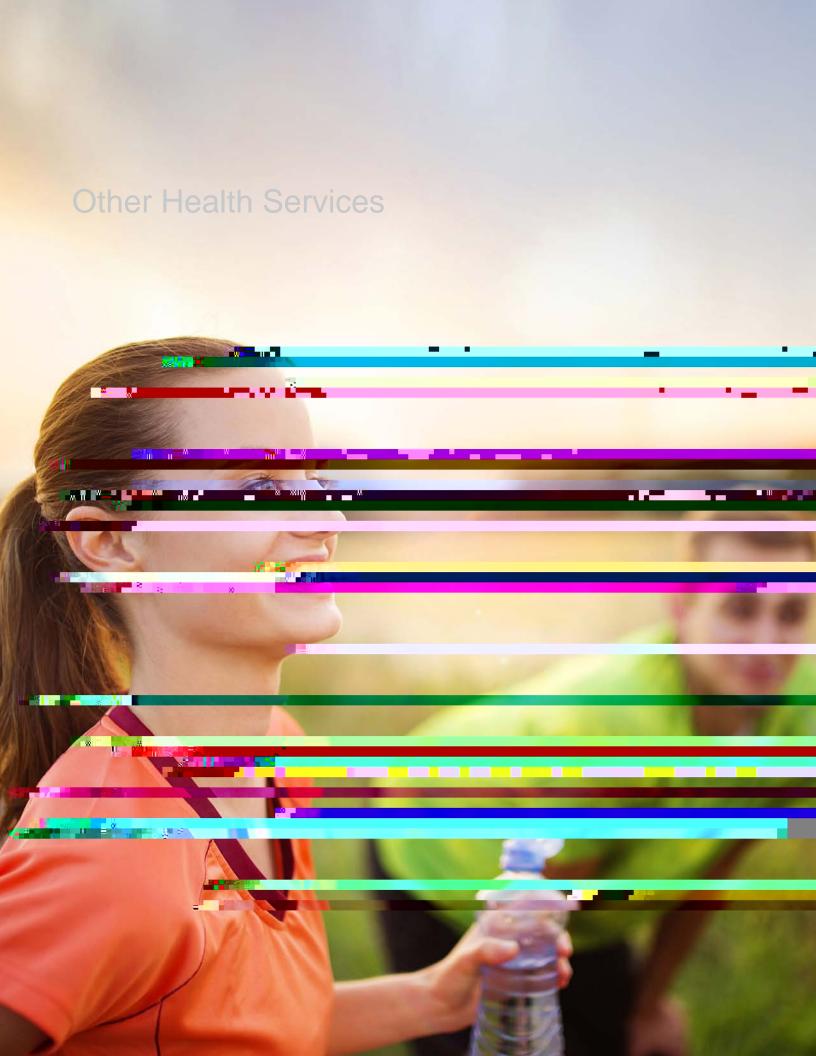
Nemours is actively involved in TrialNet, an international network of leading academic institutions, physicians, scientists and health care teams dedicated to the prevention of Type 1 diabetes. TrialNet offers risk screening for relatives of people with type 1 diabetes and innovative clinical studies to preserve insulin production.

#### Juvenile Diabetes Research Foundation

Nemours takes great pride in research — so that we can better serve children today and in the future. For this reason, we are a dedicated partner of the Juvenile Diabetes Research Foundation, whose support is accelerating life-changing breakthroughs to cure, prevent and treat Type 1 diabetes and its complications. Over the years, Nemours representatives have served on the JDRF board, participated in the JDRF One Walk®, and provided educational resources to children and families involved with the program.

### School Partnerships & Education

Nemours nurse certi ed diabetes educators provide ongoing diabetes education and support for school nurses and caregivers throughout the state of Florida. Within the TSA, the Nemours nurse certi ed diabetes educators provide school nurses with workshop training sessions and technical assistance via telephone. In addition, Nemours assists school districts in the TSA to coordinate special accommodations for students managing diabetes.



#### SECONDARY HEALTH CONCERN

## **Oral Health**

Nearly two-thirds of children in the TSA from ages 2 to 17 (59.4 percent) have received dental care (for any reason) over the last six months. When respondents were asked to specify the reason for their child's most recent dental visit, 84.6 percent of parents mentioned a routine cleaning or checkup, while 5.3 percent described repair work or a cavity ll, 2.8 percent referenced an orthodontic appointment, and 1.2 percent indicated a tooth extraction.

Through Nemours Children's Hospital community partnerships and collaborations, Nemours recommends the following partners to provide pediatric oral health services: Community Health Centers, True Health, Orange Blossom Family Health Centers and Osceola Community Health Services.

## Sexual Health

One-fourth of Orange County high school students (25 percent) report having had sexual intercourse with at least one person during the three months preceding the administration of the 2013 Youth Risk Behavior Survey. Among Orange County high school students who are sexually active, 37.4 percent report not using a condom during their last sexual intercourse, and 21.3 percent report not using any method to prevent pregnancy.

Through NCH's community partnerships and collaborations, Nemours recommends the following partners to provide sexual health services: Community Health Centers, True Health, Orange Blossom Family Health Centers and Osceola Community Health Services.

